



On the Move

WINTER 2024 - 2025

Parkinson's and Movement Disorders Center



VCUHealth™

Fostering community, innovation and discovery to transform the future of movement disorders care



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PMDC Director and Movement Disorders
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“You matter because you are you, and you matter to the last moment of your life.”

Dame Cicely Saunders, founder of palliative care and the modern hospice movement

As we look back on a year marked by collaborative growth and innovation at the VCU Parkinson’s and Movement Disorders Center (PMDC), we are excited to share some of the remarkable strides made possible by our patients, partners and care teams. This edition showcases the power of a shared commitment to advancing care, research and education — demonstrating what can be accomplished when we work together toward a common goal.

Our partnerships outside the walls of the hospital and clinic are central to this mission. One impactful example is Gary Rogliano and his daughter, Margaret Preston, who co-founded Power Over Parkinson’s (POP) after Gary’s Parkinson’s disease (PD) diagnosis. Rogliano, a lifelong hard worker, and his family have turned their experience into action, supporting others through POP by providing financial assistance and resource connections for people with PD across central Virginia. Their partnership has been instrumental to the PMDC, most recently contributing to the development of a state-of-the-art gait lab that will enable us to explore new treatments for some of the most disabling and treatment-resistant symptoms that PD can cause.

This year’s PMDC Pilot Grants have continued to support essential research, including innovative studies like the use of Wi-Fi sensing for home-based patient monitoring. The 2nd Annual Research Symposium held in June provided a platform for pilot grant recipients and other investigators across VCU and beyond to showcase their research in PD, Alzheimer’s disease, and other neurological conditions relevant to movement disorders. In this newsletter, you’ll also hear more about investigator-initiated trials and their importance to researchers to pursue ideas that advance our understanding of and ability to treat movement disorders.

Our center’s commitment to clinical trials continues to expand. Jeff Strano, one of our patients, is a participant in the ORION trial, which is one of the first trials of its kind and seeks to determine the effectiveness of a novel treatment for Progressive Supranuclear Palsy (PSP). This trial exemplifies the PMDC’s dedication to providing patients across the spectrum of conditions we treat with access to potential treatments and to advancing the science that will shape future care.

Our outreach work has also brought the movement disorder community together as highlighted through events like the Huntington’s Disease Education Day, which included sessions on mindfulness, music therapy and self-care. Additionally, PMDC staff have expanded support groups, doubling the number of meetings held this year and reaching more individuals across a variety of movement disorder communities — from Multiple System Atrophy to Lewy body dementia. Such gatherings provide patients and their families with crucial

opportunities to connect, share and learn from each other. These serve as part of a number of data milestones that articulate the hard work of our dedicated clinical teams — who collectively played roles in supporting more than 6,000 outpatient visits this year.

Through efforts like these, we are building a more connected and empowered community for individuals affected by movement disorders. This work is only possible through the support of dedicated partners, committed researchers and engaged patients like those featured here.

Lastly, this edition includes a remembrance for Dr. Danielle Noreika, whose compassion and leadership in palliative medicine continues to inspire us. Her memory is a testament to the profound impact individuals can have in advancing care and supporting others in their most vulnerable moments.

It is this shared dedication to care, research and collaboration that continues to shape the future of movement disorder treatment and support. Thank you for being an integral part of this journey. ■

Ataxia clinic plans to expand treatment offerings

By Sean Gorman

After the VCU Parkinson's and Movement Disorder Center's ataxia clinic launched in early 2024, the patient roster grew quickly.

The clinic offers ataxia exams as well as the genetic testing that can confirm what specific form of the disorder a patient may have.

The PMDC now has 70 ataxia patients at the clinic, which is a very large number for a group of rare disorders, says Stephanie Bissonnette, D.O., a PMDC movement disorders neurologist who oversees the clinic along with PMDC genetic counselor Ginger Norris, M.G.C.

The PMDC clinic, which also sees patients with other movements disorders like Parkinson's disease, dystonia and Huntington's disease, helps ataxia patients navigate a vast and complicated array of testing options to find the ones that have the most promise in unlocking a firm diagnosis.

That makes the clinic a valuable resource for patients living with ataxia, which includes a wide range of often-undiagnosed disorders characterized by coordination problems, balance issues and other symptoms. Those symptoms can often be mistaken for having other

causes, such as alcohol use, clumsiness or Parkinson's disease, Bissonnette says.

"It's really hard to say, 'you very clearly have these specific symptoms, so you must have this type of ataxia,'" Bissonnette says. "Genetics is a big part of it because there are so many ways you can inherit ataxia. That also complicates how you get the testing. There's not one test. There are many tests and many companies, and they all look at very different things."

And finally having confirmation of which specific form of ataxia a patient has offers clarity for what they're facing and guides their care, Bissonnette adds.

Since so many ataxias have no cure, treatment involves therapeutic interventions to preserve muscle movement and coordination, Bissonnette says. So the next phase of the clinic is focusing on how to provide comprehensive care for patients from a range of medical providers.

Bissonnette says that by the summer of 2025, the clinic hopes to offer occupational, speech, and physical therapy as well as social worker services for ataxia patients at the PMDC's Short Pump location.



Stephanie Bissonnette, D.O.

"The goal is to keep people living the best quality of life for as long as possible," Bissonnette adds.

The clinic also serves as the nidus for ataxia research and future clinical trials that could unlock better ways to treat ataxia, Bissonnette adds.

"Being able to be a central location where people can go and get their genetic testing or their physical therapy evaluations and things like that means that we can now start to do clinical trials with patients because we'll have enough patients to do those trials," Bissonnette says. "I think the research component is going to be really important. The patient outreach has already started because the patients are interested in getting to know each other and getting to share their stories." ■



2024 PMDC Research Symposium highlights movement disorders research at VCU

The VCU Parkinson's and Movement Disorders Center's 2nd Annual Research Symposium delved deep into studies being conducted across campus and beyond to reveal more insights into understanding and treating movement disorders and related neurological conditions.

About 75 people attended the June 14 event at the VCU College of Health Professions building in downtown Richmond. The symposium featured presentations from researchers who have received PMDC Pilot Grants, which help fund studies that seek to better understand movement disorders like Parkinson's disease as well as other neurodegenerative disorders such as Alzheimer's disease. Over the last several years, the center has provided nearly \$750,000 in funding for 16 innovative pilot grant studies to date.

"The symposium is a chance to promote the incredible research going on under the PMDC umbrella," says Bonnie Mahl, PMDC's senior community engagement and outreach coordinator. "It offers researchers

a space to present their findings, and it's a way to showcase movement disorders studies happening on the VCU campus as well as with collaborators from the U.S. Department of Veterans Affairs and the College of William & Mary."

The 2024 symposium featured more than a third more speakers and poster presentations than the prior year, Mahl notes.

PMDC Director Brian Berman, M.D., welcomed attendees before turning the microphone over to eight presenters. Among the speakers were Sarah Lageman, Ph.D., a PMDC neuropsychologist who examined group-based intervention to treat insomnia in patients living with Parkinson's Disease, and Gang Zhou, Ph.D., with William & Mary's Department of Computer Science, who discussed findings from a study that examined brain cell firing changes associated with freezing of gait in Parkinson's patients.

Other speakers were from the PMDC and from a broader VCU community,

including speakers from the Departments of Surgery, Biology, Neurosurgery and Pharmacotherapy and Outcomes Science.

Following the speaker sessions, attendees mingled with each other and with 14 basic science and clinical translational researchers who presented their scientific posters in the building's lobby. Poster topics ranged from rat models of Parkinson's disease to the development of a clinical research ataxia program, which was presented by PMDC movement disorders neurologist Stephanie Bissonnette, D.O. Other posters examined how to improve caregiver-Alzheimer's patient relationships, the development of a clinic for veterans who have movement disorders and investigation of novel deep brain stimulation targets to improve cognition.

"People attending come from different colleges across VCU's campus, so the symposium offers opportunities for networking and further collaboration," Mahl says. ■

PMDC team shines at leading international medical conference

Members of the VCU Parkinson's and Movement Disorders Center's team were among thousands who attended the 2024 MDS International Congress of Parkinson's Disease and Movement Disorders in Philadelphia this past fall.

Sponsored by the International Parkinson and Movement Disorder Society, organizers note that the congress is a global gathering of clinicians, students and health care professionals that is regarded as the premier annual forum for learning the latest clinical and scientific insights into movement disorders. The event, held from Sept. 27 to Oct. 1, also provides a venue for networking and collaboration among experts in the field.

More than 1,800 abstracts were presented at the congress, including a half-dozen studies from the VCU PMDC.

Representing the PMDC were Director Brian Berman, M.D., Movement Disorders Neurologist Matthew Barrett, M.D., Post-Doctoral Research Fellow Ahmed Negida, M.D., Ph.D., Movement Disorders Fellow Diana Hancock, M.D. and Clinical Research Coordinator Caleigh Dintino, B.S.

Berman and Dintino presented a poster at the forum on the correlation of gamma-aminobutyric acid (GABA) and glutamate levels with symptom severity in individuals with cervical dystonia. Barrett presented posters about cognitive performance and Lewy body diseases and about interdisciplinary care for atypical Parkinsonism. Negida and Barrett also presented a poster about Parkinson's disease with mild cognitive impairment. ■

VCU PMDC patient raises funds to support dystonia awareness

By Sean Gorman

Steve Swarr's advocacy for dystonia awareness has taken him to Capitol Hill to lobby lawmakers for federal money to unlock further research into the movement disorder he was diagnosed with decades ago.

And on Sept. 14, it took him on a mini safari of sorts at the NOVA Wild zoo near his Ashburn, Va., home. Through that fundraising event, Swarr generated more than \$5,000 in donations to support the Dystonia Medical Research Foundation, a nonprofit that raises awareness about the disorder while working to find more ways to treat it.

The event was the latest awareness event for Swarr, a patient at the VCU Parkinson's and Movement Disorders Center who has been volunteering for dystonia support causes for about a decade.

"It's a great way to meet other people with dystonia and to meet everybody who's really actively involved and trying to do research and raise money for treatments," Swarr says.

Event offers support, raises awareness

The Dystonia Medical Research Foundation organizes the Dystonia Zoo Day event every year to bring patients and families from around Virginia, Maryland and Washington, D.C. for group tours of the Northern Virginia zoo.

In advance of the outing, Swarr reached out to businesses, organizations and individual donors to raise money for the research foundation. Swarr came to the event with a group of about 15 family members and friends.

"They know what I've been going through for the past four decades," says Swarr, a 53-year-old environmental engineer. "We just had a fun day at the zoo."

Caileigh Dintino, a PMDC clinical research coordinator, also traveled up from Richmond to show support by taking part in the Zoo Day event. To thank Dintino for making the trip, Swarr gave her a painting he made of the Northern Lights.

A mystery ailment and a diagnosis

Swarr learned more than 40 years ago that he has cervical dystonia, which causes involuntary contractions in his neck and back muscles. Swarr was 12 years old at the time and started to experience neck pain along with tightening muscles that shifted his posture.

"They didn't know what it was at the time. My doctors couldn't figure it out. I eventually got diagnosed with dystonia and was in a wheelchair for about a year at the hospital," Swarr says. "I've been in and out of doctors' offices for pretty much my whole life dealing with this. I've also seen a progression in better treatment and better awareness."

Swarr, who also has essential tremor, had deep brain stimulation probes implanted years ago that addresses the symptoms caused by that condition as well as those caused by dystonia.

He regularly travels to Richmond to see PMDC Director Brian Berman, M.D., for treatment that includes botulinum toxin injections to ease Swarr's dystonia symptoms by calming his muscles and lessening the intensity of muscle contractions.

"It gives you more control over your body," Swarr says of the injections. "I can have more control over my head, and I'm able to hold my head a little bit straighter. I'm able to work and be more productive."



A participant at the 2024 Dystonia Zoo Day event at the NOVA Wild zoo.

Swarr adds that he's in good hands getting care from Berman.

"He's a good doctor. He's very personable. And he knows dystonia really well. He's got a wealth of knowledge," Swarr says. "He'll tell you what he thinks, but he also says 'it's your body. You decide what you want to do'. And he's very open to listening, which I appreciate."

Swarr says he's planning to spread the word about the Zoo Day event next year among those like him who are living with dystonia. And he's grateful to have been able to have raised the amount he did at this year's event.

"Anything that I can do to support the cause makes me feel good," he says. "I do what I can." ■

PMDC outreach events boost support for movement disorders community

By Sean Gorman

People living with Huntington's disease gathered at the Bon Air United Methodist Church on Sept. 21 for a full day of programming brought to them by the VCU Parkinson's and Movement Disorders Center (PMDC) and partnering organizations.

There were sessions about mindfulness, therapy animals, chair yoga, the therapeutic power of music and self-care at that Huntington's Disease Education Day event.

"It was very interactive, which was really cool," says Bonnie Mahl, PMDC's senior community engagement and outreach coordinator. "At the end of the day, everyone was able to share and learn from each other. That was awesome."

The gathering was just one of the many efforts the PMDC undertook in the latter half of 2024 to boost support for those living with a wide range of movement disorders and their care providers.

In 2024, a series of educational events offered insights on living with Parkinson's disease. These included a September seminar that PMDC Neuropsychologist Sarah Lageman, Ph.D., presented in Culpeper, Va., on how to manage the

cognitive and mood symptoms of that disease. In October, PMDC Nurse Navigator Annie Coy, RN, delved into how to curb the costs of Parkinson's medications at a Power Over Parkinson's event held at Henrico's Libbie Mill Library. And coming up on April 12, 2025, the PMDC will be holding its annual Parkinson's Disease Education Day.

While programming for people with Parkinson's and Huntington's continues to be a crucial part of the PMDC's mission, the center has also been working to expand support for people with other movement disorders like Multiple System Atrophy (MSA), Lewy body dementia (LBD), Progressive Supranuclear Palsy (PSP), and dystonia.

"They're all well-attended," Mahl says. "We're definitely furthering our reach into the community."

In addition to holding its Multiple System Atrophy Education Day on Oct. 26, the PMDC helped organize seminars in July and August about managing MSA symptoms using physical therapy and other approaches.

In addition to organizing a full slate of educational events in 2024, the PMDC also increased the number of its support groups that bring a large variety of movement disorder patients together regularly to talk about their conditions and the issues they face in their daily lives.

"At the end of the day, everyone was able to share and learn from each other."

Throughout 2024, the number of PMDC-led support group meetings more than doubled from 2023. Some of the meetings were virtual while others were held in person or through a hybrid of virtual and in-person meetings.

"Being able to talk with someone who can relate to you and your disease just adds so much more insight," Mahl says. "You feel validated. People just need a space where they can be heard and be seen. Our support groups provide that." ■



Honoring Danielle M. Noreika

By Brian Berman

The entire VCU community was shocked and saddened by the unexpected passing of Danielle M. Noreika, M.D., in October. Dr. Noreika was a beloved palliative care physician at VCU, served as the Section Chief of Palliative Medicine and as Program Director of the VCU Health Hospice and Palliative Medicine Fellowship program.

I first connected with Dr. Noreika in July of 2021 and discussed the idea of developing a multidisciplinary neuropalliative care clinic within the PMDC to help bring more supportive care options to our movement disorders patients. She responded to me the very next day to say she was interested and asked to meet to discuss the idea further.

We went on to create a PMDC-based "Supportive Care Clinic" that involved Dr. Noreika and her team, including a palliative care fellow, social worker, nurse navigator along with an

advance care planning specialist. In early 2024, Dr. Noreika helped combine the PMDC Supportive Care Clinic with our Progressive Supranuclear Palsy Center of Care clinic and worked with the PMDC's Matthew Barrett, M.D., to help better serve this patient population with palliative care needs until her passing.

In July 2023, I was invited to serve on Dr. Noreika's promotion committee. It was an easy decision by the committee to recommend her promotion to full Professor in recognition of all her significant contributions to the field of palliative medicine.

On a personal level, Dr. Noreika exuded the very best attributes of a clinician. She was dedicated to serving patients and intensely focused on improving their quality of life through the prevention and relief of suffering. She was a positive and extremely caring and passionate person and an easy friend. She touched innumerable lives — including many in the PMDC community — and will be sorely missed by everyone who had the good fortune to interact with her before her passing. ■

Rogliano family bolsters support with \$250,000 for gait study Center



People with Parkinson's disease in Greater Richmond — and those beyond the region — can be thankful to count Gary Rogliano among their ranks.

Diagnosed with PD in May 2018, Rogliano is a highly successful entrepreneur who in the last nearly seven years has made fighting the disease — and helping fund research into preventing it — his primary venture.

"I was lucky in business, so I figured let me try to give it back to help the people with Parkinson's," Rogliano said recently from his estate in Goochland County, Va. During his career, Rogliano was involved in global ventures and industries, even founding an airline.

Today, he is founder and chairman of Power Over Parkinson's, or POP. The Richmond-based nonprofit offers exercise, education and socialization for people with PD and other neurodegenerative disorders. His daughter, Margaret Preston (who lives across a wooded stream beside his home), serves as president.

POP's goal: Reduce PD symptoms, slow the progression of disease and give people living with the condition a connection to others with PD through events and activities around town. Many of its events are in partnership with the VCU Parkinson's and Movement Disorders Center (PMDC) and its

specialists. Rogliano says POP helps fill the gap between doctors' visits and multiple-times-daily medication doses for patients, giving them an outlet to build relationships with others living with the condition.

And in 2024, the Rogliano family deepened their commitment to the cause, with a \$250,000 gift to the PMDC. Their funding will create the Gait Collective at VCU to study freezing of gait.

Typically, gait is an autonomic movement people don't think about; PD patients, like Rogliano in recent years, often must think about how to move, walk or get in or out of bed. He notes that small changes in the floor — from carpet to wood, for example — cause him to freeze and consider how to maneuver from one material to the other.

"We have only limited time with patients, so creating a Gait Collective will help us more thoroughly analyze people's walking problems, the root causes, look at data and trends and really come up with a comprehensive plan to help people dealing with gait," says Leslie Cloud, M.D., who serves as the Rogliano Family Endowed Chair and directs the PMDC's Parkinson's disease program. The gift will support research grants and collect additional contributions to build on the initial funding.

Hopefully, the work out of the Gait Collective will someday lead to a helpful product or therapeutic to combat gait issues, Preston says. Cloud notes calling the initiative a Gait "Collective" means it's open to other gait experts around the world for research collaboration.

Beyond the gift to the PMDC, Preston and her father continue to build POP. Its Parkinson's Activity League (PAL) brings people with PD together at regular events. PAL is free to attend for people with PD, "and is one of my favorite programs because that's really where

the relationships happen," Preston says. "Because you cannot feel alone in navigating this disease. At PAL, you're among your people. It's a support group on steroids."

POP has expanded from four wellness and exercise classes a week to 10 between Henrico and Chesterfield counties. POP also holds educational seminars throughout the year tailored to community interests (a recent educational event discussed "Parkinson's burnout" to address the constant demands of minding meds, exercise, nutrition and even talking about the disease).

"Gary and his family's impact is so much greater than only VCU," Cloud says. "What they do for people with Parkinson's disease is unparalleled. They have provided people with PD a community that wasn't here before and are providing opportunities for people to engage in beneficial activities while building that sense of community."

Rogliano's only requirement for those who participate in POP's programs: Exercise. Cardio, in particular, is one of the only methods of slowing PD's progression.

"I don't care what you do or where you do it, just do it," says Rogliano, who works out at least two hours a day — treadmill, weights, swimming and boxing. He even exercises at his home gym or pool before attending POP classes.

"We charge nothing for anything we do. I don't want anybody not to get what they need because of financial conditions. That's off the table," he says. "We want people to get the care they need without any financial barriers."

And, he jokes: "If you don't like it, I'll give you your money back." ■

PMDC 2024 STATS

NOVEMBER 1, 2023 - OCTOBER 31, 2024

\$707,517

TOTAL PHILANTHROPIC FUNDS COMMITTED

255

DISTINCT DONOR COUNT

6

MULTIDISCIPLINARY CLINICS

- Complex Parkinson's Disease
- Progressive Supranuclear Palsy and Corticobasal Syndrome
- Huntington's Disease
- Alzheimer's Disease and Related Dementias
- Multiple System Atrophy and Autonomic Disorders
- Ataxia

EDUCATION & TRAINING

Patient Education

- HD Patient Education Day
- MSA Patient Education Day

Provider Education

- PD Provider Symposium
- 2nd Annual PMDC Symposium

Fellows and Post Docs

- 1 current Fellow, Diana Hancock, M.D.
- 2 Matched Fellows (1 starting Jan 2025; 1 starting July 2025)
- 1 Research Post Doc, Ahmed Negida, M.D., Ph.D.

OUTREACH

5 Support Groups

- Women and Parkinson's Disease Support Group
- Huntington's Disease Support Group
- Lewy Body Dementia (LBD) Caregivers Support Group (*New*)
- Dystonia Support Group (*New*)
- Cure PSP Support Group (*New*)

CLINICAL IMPACT

Deep Brain Simulation (DBS) procedures and patients

- 71 procedures
- 70 individual patients

Outpatient visits

- 6,285 total
- 907 new patient visits
- 3,824 return patient visits
- 2,939 individual patients

Number of patients by diagnosis

- 1541 Parkinson's Disease
- 310 Dystonia
- 294 Essential Tremor
- 108 Alzheimer's Disease

- 89 Restless Legs Syndrome
- 87 Dementia with Lewy Bodies
- 84 Atypical Parkinsonian Disorder
- 69 Ataxia
- 68 Huntington's Disease
- 37 Hemifacial Spasm
- 32 Tourette Syndrome

Number of botulinum toxin injections

- 898 procedures
- 201 individual patients

Neuropsychology

- 945 neuropsychological tests
- 874 therapy sessions

13 Patient Education Sessions

- Parkinson's Disease and Travel; *in partnership with Virginia State Parks*
- Financial Planning and Parkinson's Disease Workshop; *in partnership with Power Over Parkinson's (POP)*
- APDA Good Start part I; *in partnership with VA APDA*
- APDA Good Start part II; *in partnership with VA APDA*
- May MSA Seminar, "Treatment of motor symptoms of MS"
- June MSA Seminar, "Mood and coping strategies for patients and caregivers"
- Eyes and Parkinson's Disease; *in partnership with Power Over Parkinson's (POP)*
- July MSA Seminar, "Role of physical therapy in MSA"
- Ataxia Focus Group
- August MSA Seminar, "Management of autonomic symptoms in MSA"
- Dr. Lageman Orange County PD Support Group Talk
- Sept. MSA Seminar, "Management of sleep issues in MSA"
- PD and Medication; *in partnership with Power Over Parkinson's (POP)*

EDUCATION & TRAINING, continued

Continuing Medical Education (CME) activities for providers

Parkinson's Disease Symposium for Providers April 27, 2024

PMDC Education Conference Series

- "Evidence and clinical practice processes for disease-modifying therapies in Alzheimer's disease" - Hamid Okhravi, M.D. and Bahar Niknejad, M.D. - November 2023
- "Effect of neuroanatomy and functional connectivity on transcranial magnetic stimulation (TMS) motor responses" - Ravi L. Hadimani, Ph.D. - December 2023
- "Sleep and circadian disruption induce accelerated aging across multiple physiological systems" - Josiane Broussard, Ph.D. - February 2024
- "Role of environmentally-relevant toxin exposures and epigenetic mechanisms in neurodegenerative disorders" - Laxmikant Deshpande, Ph.D. and Joseph McClay, Ph.D., - April 2024
- "Seeing the mechanisms: Imaging influx and efflux of cerebrospinal fluid in mice" - Douglas H. Kelley, Ph.D. - May 2024
- "Using multimodal brain imaging and advanced data models to study neurodegenerative diseases"- Ahmed Negida, M.D., Ph.D. - August 2024

RESEARCH

4 Foundation-sponsored Center of Excellence (COE) designations

- Parkinson Foundation COE
- HDSA COE
- PSP Center of Care
- MSA COE

Active studies

(clinical trials vs. investigator-initiated research)

- 30 active clinical research studies
- 14 Investigator-initiated studies
- 16 Industry-sponsored clinical trials

Total research funding

- \$6,671,101.30

Number of pilot grants (2024-2025 cycle)

- 11 applications, 5 awarded

Total funding for pilot grants awarded

- \$244,539 awarded for pilot grants this cycle
- \$742,205 in total funding for the 15 pilot grants awarded since 2021

PMDC study to explore a potential cervical dystonia treatment

By Sean Gorman

For those with cervical dystonia, botulinum toxin injections are a common treatment that help address the symptoms of a disorder that constricts their neck muscles, frequently causing pain while limiting their range of motion and impacting their posture.

Although the injections do provide some relief of dystonia, they can often cause intolerable side effects, and the benefits of the injections are limited and temporary — with positive effects typically wearing off before the next set of injections.

Another treatment, deep brain stimulation, can be used when cervical dystonia symptoms do not respond to standard therapies, but it's an invasive procedure with its own drawbacks, including side effects and limited benefits.

A \$500,000 investigator-initiated research trial at the VCU Parkinson's and Movement Disorders Center is exploring a new way to help relieve cervical dystonia symptoms in those individuals who continue to have symptoms that disrupt their everyday life.

PMDC Director Brian Berman, M.D., the study's principal investigator, says the double-blind placebo-controlled trial will gather preliminary findings on whether the drug valbenazine could be a safe and effective treatment for chronic dystonia symptoms when paired with botulinum toxin injections.

"New treatment approaches for cervical dystonia are desperately needed to alleviate symptoms and improve the quality of life for the many people who suffer from this incurable and disabling neurological disorder," Berman says.

While beneficial in treating tardive dyskinesia, a disorder of involuntary movements in a patient's face or body caused by antipsychotic medications, valbenazine has not previously undergone evaluation in a placebo-controlled clinical study in cervical dystonia patients, Berman notes.

Research Could Unlock Further Study

Berman is pursuing the research through an "investigator-initiated research trial" that he proposed. That approach provides medical professionals a path to get the ball rolling on a potential new therapy by generating initial findings that can become the foundation for a larger and more extensive clinical trial.

"It's the way doctors and researchers can propose something new that a pharmaceutical company isn't ready to invest a lot of money in through a big clinical trial until they see some promising sample data," Berman says.

Berman's hypothesis is that valbenazine will not only be well tolerated by patients, but that it will also lessen the severity of their cervical dystonia symptoms during the 26-week trial.

If the results are promising, that could open the door to more research on the drug's usefulness in alleviating symptoms in cervical dystonia patients. ■

Fourth annual PMDC pilot grants fund record number of studies

By Grace McOmber, School of Medicine

The VCU Parkinson's and Movement Disorders Center (PMDC) in 2024 awarded funding to five studies, the largest number since the pilot grant program's founding in 2021, broadening the program's impact on movement disorders research at VCU. The PMDC Pilot Grants Program receives funding support from the Commonwealth of Virginia, The Joan & Morgan Massey Foundation, The Johnson Family Fund for Essential Tremor Research and community donors.

The 2024 awardees represent the multidisciplinary nature of research, with faculty from the VCU School of Medicine, College of Engineering, College of Humanities and Sciences and School of Nursing. This year's recipients also include faculty from the College of William and Mary's Department of Computer Sciences.

"We're continuing to reach a broad range of investigators across the School of Medicine, VCU and beyond," says Brian Berman, M.D., director of the PMDC. "Our ability to make advances toward a cure requires having good models to understand the disease and having a breadth of investigators and departments certainly helps that pursuit."

This year's funded studies include investigations into the safe use of Wi-Fi for Parkinson's monitoring, a novel use of deep-brain stimulation to treat a debilitating symptom of Parkinson's disease and funding for benchtop science projects investigating the pathogenesis of Parkinson's disease. This award cycle also features a mentor-mentee team of a postdoctoral student and his faculty advisor, which advances the PMDC's mission to foster the next generation of movement disorders researchers.

"The tech-forward aspect of this year's awards is one of the most exciting aspects to see," Berman says. "There's a lot of potential for artificial intelligence and other technologies to advance care for patients with movement disorders and beyond."

PMDC PILOT GRANT AWARDEES 2024-2025

Conserved essential genes as pro-neuroprotective targets: Getting out from under the lamppost

Rohil Hameed, Ph.D., postdoctoral fellow, Department of Biology, VCU College of Humanities and Sciences

Alaattin Kaya, Ph.D., assistant professor, Department of Biology, Department of Human and Molecular Genetics, VCU College of Humanities and Sciences and VCU School of Medicine

This proposal seeks to examine the potential for over-expression of essential genes to modify phenotypes associated with Parkinson's disease models in *Caenorhabditis elegans*. Due to their essential nature, this class of genes are very much understudied in genetic models as, traditionally, loss-of-function mutations or reduced expression is the most common approach to examine the roles of candidate genes, an approach which leads to lethality with an essential gene. The investigator proposes to use two Parkinson's disease models, previously published by other groups. Identification of genes that modulate phenotypes in the two models will represent candidate genes not previously identified that may play a role in the pathology of Parkinson's disease.

Transformer-based anomaly detection to predict freezing-of-gait from GPi local field potentials and ankle IMU data

Dean J. Krusienski, Ph.D., professor and graduate program director, Department of Biomedical Engineering, VCU College of Engineering

Gang Zhou, Ph.D., Department of Computer Science, William and Mary Arts & Sciences

Huajie Shao, Ph.D., Department of Computer Science, William and Mary Arts & Sciences

Kathryn Holloway, M.D., professor and director, Department of Neurosurgery, VCU School of Medicine

Leslie Cloud, M.D., professor, Rogliano Family Endowed Chair and director of Parkinson's disease program, Department of Neurology, VCU School of Medicine
Ingrid Pretzer-Abhoff, Ph.D., R.N., professor, Department of Adult Health and Nursing Systems, VCU School of Nursing
Harsh Shah, M.D., Department of Neurosurgery, VCU School of Medicine

Freezing of gait (FoG) is among the most debilitating manifestations of Parkinson's disease (PD) but is also relatively poorly understood and difficult to treat. This study will attempt to train machine learning (ML) architectures to reliably

detect FoG episodes by combining changes in LFPs monitored by deep brain stimulation (DBS) with globus pallidus internus (GPi) leads with abnormalities in kinematic data provided by wearable inertial motion units (IMUs). Expert review of video of participant physical performance will be completed to confirm flagged episodes of FoG compared to periods of normal walking and standing.

Examination of a GBA-RTK- α -Synuclein axis in cellular and preclinical models of Parkinson's disease

Santiago Lima, Ph.D., associate professor, Department of Biology, VCU College of Humanities and Sciences

Jason Newton, Ph.D., assistant professor, Department of Biology, VCU College of Humanities and Sciences

Building on their 2023 PMDC pilot grant-funded project that helped them develop a GBA knockout cell model with increased α -synuclein accumulation, Lima and Newton aim to now explore how GBA activity defects and associated glycosphingolipid alterations influence Trk receptor activity and impact cell survival. Establishing a link between GBA-related mechanisms and the altered

kinase signaling pathway contribution to Parkinson's disease pathogenesis would provide greater insight into pathogenesis of Parkinson's disease and perhaps lead to identification of potential novel therapeutic targets.

At-home monitoring of Parkinson's disease patients through non-invasive Wi-Fi sensing

Eyuphan Bulut, Ph.D., Associate Professor, Department of Computer Science, VCU College of Engineering

Brian D. Berman, M.D., M.S., Professor and Bemiss Endowed Chair, Director, VCU Parkinson's and Movement Disorders Center, Division of Movement Disorders Chief, Department of Neurology, VCU School of Medicine

This proposal outlines a pilot study aimed at developing and testing a non-invasive, low-cost and privacy-preserving system for monitoring Parkinson's disease (PD) patients at home using Wi-Fi sensing technology. The system intends to track PD-related symptoms, such as tremors and motor fluctuations, by analyzing the channel state information (CSI) from Wi-Fi signals. The project aims to improve the monitoring of PD patients, provide better insights into the effectiveness of medications and ultimately enhance patient outcomes.

Physical adversarial attacks on Wi-Fi sensing systems for monitoring Parkinson's disease patients

Changqing Luo, Ph.D., assistant professor, Department of Computer Science, VCU College of Engineering

Wi-Fi sensing systems are especially vulnerable to physical adversarial attacks, such as signal manipulation, due to the open-air transmission of signals, which can disrupt input data. This proposal aims to explore and design unnoticeable over-the-air physical attacks on Wi-Fi sensing systems used for monitoring Parkinson's disease (PD) patients. The research focuses on understanding the vulnerabilities in machine learning (ML) models used in these systems and devising attack strategies to disrupt the accurate monitoring of PD patient movements. The proposal addresses a critical gap in the security of Wi-Fi sensing systems by investigating physical adversarial attacks, which can compromise the effectiveness of these systems in monitoring PD patients.



Man taking part in PMDC clinical trial hopes study unlocks answers on treating PSP

By Sean Gorman

A couple years ago, Jeff Strano could tell his balance didn't seem quite right as he walked.

"My gait was a little off," Strano says. "I was kind of dragging my left foot. I was kind of lethargic. I had a lot of anxiety and stress."

Strano, 55, was initially diagnosed with Parkinson's disease, but that determination didn't end the search for the underlying cause of his symptoms. His Parkinson's medications didn't seem to be having much effect, so he went to another doctor for more testing that revealed a new finding.

"He specializes in Progressive Supranuclear Palsy, and he recognized some structures in my brain were abnormal," Strano says.

In January 2024, Strano learned that testing showed he does indeed have Progressive Supranuclear Palsy (PSP), a rare neurodegenerative disease. With no known cure and a lack of drugs available to treat the disorder, Strano searched for clinical trials on the website for the Cure PSP nonprofit group.

That led him to the VCU Parkinson's and Movement Disorders Center (PMDC), where Strano is taking part in the center's first PSP clinical trial to test a treatment being developed to stall the onset of PSP and symptoms that can include problems swallowing, muscle stiffness, balance problems and other issues.

"I hope the treatment slows the progression of the disease because it seems like it's moving pretty quickly," Strano says of the disorder's impact on him.

Known as the ORION trial, the study is looking at whether the investigational drug, called AMX-0035, is safe and

effective at treating PSP. The PMDC is one of numerous locations in the U.S. and Europe that are taking part in the trial.

About 110 patients across all the trial sites will be part of the initial phase of the study, says Matthew Barrett, M.D., the study's principal investigator at the PMDC. About 75% of those patients have been enrolled in the study. If the preliminary results are positive, Barrett says an additional 600 to 800 patients will be added into the clinical trial.

Barrett says researchers hope to find a treatment that can slow PSP and its impacts on patients. Among the reasons the center was chosen to be part of the study, Barrett says, are the clinics that the center runs for PSP patients in Short Pump as well as the PMDC's designation as a CurePSP Center of Care that provides high-quality care for those with the disorder.

"It's critical for patients to participate in clinical research," Barrett says. "Without that, we can't improve the available medical treatments for patients."

Strano started taking part in the trial in September, traveling from his Springfield, Va., home to the PMDC for motor skills exams, cognitive evaluation and other testing.

As someone living with the disorder, Strano knows his experience can help researchers get valuable insights during the clinical trial.

"It's a rare disease, and there's no known cure as of now," Strano says. "I want to do anything I can do to help people learn more about how to treat it." ■

HAVE YOU CHECKED OUT OUR NEW WEBSITE?

This year, the PMDC launched a new and improved website. The project aligns with our mission to care for and inform individuals with movement disorders, their families and the broader community.

With its fresh design, intuitive navigation and enhanced functionality, the site provides easy access to information about our specialty care and clinics as well as introductions to our dedicated team. Our incredible patients take center stage with inspiring stories that highlight their journeys and resilience.

Visitors can also stay informed by signing up for updates to learn about our latest advancements in care, research, education and outreach and to explore ways to support the PMDC's mission.

We invite you to visit our new website today to discover more about the work we do and the lives we touch.



Support the PMDC

Find all the ways you can support our work to transform current treatment models for movement disorders.

Philanthropy plays an important role in bolstering our multidisciplinary clinical team, funding innovative research and supporting our training and outreach efforts. For information about how you can support the VCU PMDC, please contact the Neuroscience Development Team at 804-628-2022 or vcuhealthdevelopment@vcuhealth.org.

parkinsons.vcu.edu/support-our-work/give/

To opt out of receiving fundraising communications from VCU Health, contact 1-844-445-9126 or FundraisingOptOut@VCUHealth.org.



Movement disorders conference offers insights for PMDC attendees

Two members of the PMDC team were in Aspen, Colo. this summer taking part in a conference for movement disorders clinical practitioners.

Annie Coy, RN, and Mairead Busic, NP, said the International Parkinson and Movement Disorder Society's July 28-Aug. 1 conference offered the chance to learn from unique case studies while networking with leaders in the movement disorders field.

Among the topics discussed, organizers say, were how to spot and classify parkinsonism, tremor and other disorders as well as treatment options for a wide range of movement disorders.

"It was a comprehensive review of movement disorders and was a huge knowledge boost," Busic says.

Coy, the PMDC's nurse navigator, says the main benefits of attending were the insights offered during expert lectures and the case studies presented. Coy adds the event was a reminder of the intricacy of the movement disorders field.

"While having worked in movement disorders neurology for almost 10 years, this conference reminded me that no matter how much you've already seen, there is always something new to learn!" Coy says.

Busic says that while at the conference, she and Coy were able to enjoy the beauty of the area, including visits to the John Denver Sanctuary and Aspen Mountain.

"It was very cool to be in the company of and to learn from esteemed leaders in the movement disorders community," Busic says. ■



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